Statement of Rep. Dave Weldon, M.D. (FL-15)
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Thank you for the opportunity to testify before the Subcommittee and to discuss the issues surrounding the rights of the vulnerable, our responsibilities to protect the vulnerable in end-of-life decisions, and the nexus of federal health programs with regard to protecting vulnerable adults.

As you know, I introduced H.R. 1151, legislation designed to give greater legal scrutiny to incapacitated individuals in situations like that of Terri Schiavo, to ensure that before their life is ended by depriving them of necessary fluids and nutrition, a final review was granted through the federal courts.

I want to thank Chairman Souder, Ranking Member Cummings, and Mr. Davis for co-sponsoring that legislation. In addition, I am thankful for the broad spectrum of support we received on this issue from such people as Rev.

Jesse Jackson, Ralph Nader, Nat Hentoff and others. This issue we are about to discuss today transcends party labels.

By introducing H.R. 1151, I was attempting to address the deficiencies of a system that advocates starvation and dehydration of those who are dependent on others for their care.

While many have taken from the Terri Schiavo tragedy a heightened interest in living wills, I believe it would be wise for us to broaden that discussion beyond legal documents. I was shocked to learn in a recently released report that 80 percent of states now allow doctors and hospitals to controvert the expressed wishes of individuals in those written legal wills and advanced directives.

No, the problem goes deeper than not having the proper forms. That same report goes on to say that, quote, "Increasingly, health care providers who consider a patient's "quality of life" too low are denying life-

preserving measures against the will of patients and families – and the laws of most states provide no effective protection against this involuntary denial."

I encourage this committee to look at and consider deficiencies that exist in federal law setting conditions for participation in the Medicare and Medicaid programs and how essential care such as food and fluids are being dispensed. Medicare considers the provision of food and fluids through a feeding tube as a prosthetic medical intervention. Yet, the enforcement of this requirement is clearly lacking.

To address this weakness, I believe it is imperative to create a substantive standard addressing when food and fluids can be withdrawn to ensure that the rights of incapacitated individuals are not violated.

In my view, that standard would presume that vulnerable adults would want to be fed and given fluids unless they

had explicitly expressed otherwise. It is important that we err on the side of providing this type of care in the absence of an explicit written directive, and that this federal standard be expressed clearly to all health providers.

Our legal system is weighted very heavily toward ensuring that we do not convict the wrong person, and we are improving upon this system every day with the addition of DNA evidence in particular.

Should we not also as a society err on the side of preserving the life of an incapacitated individual? Incapacitation is not something any of us would choose, but to bring about an end to that condition based on hearsay or anecdotal evidence should not be sufficient in the eyes of any court or legislative body.

The lack of a standard that says we ought not starve incapacitated persons to death is in part the result of a chilling trend that substitutes utilitarian judgments of medical ethicists for the minimal care and compassion

required to simply feed someone and provide them with water.

This march toward re-defining humanity and classifying the incapacitated as “non-persons” is a dangerous step that strips the most vulnerable of the founding principles on which this country was founded. We must be careful as a nation, not to travel down the perilous path of nations that have treated those with disabilities, including those with severe brain damage, as less than whole persons. History has not judged favorably those societies.

This utilitarian trend plays into the epidemic of elder abuse and neglect occurring in many long-term care facilities around America. What is needed is accurate data and information about gaps in detection, investigation, and intervention into the neglect and exploitation of vulnerable and incapacitated adults wherever it may occur.

With this committee’s assistance, it is my desire to

introduce legislation that would address the needs and deficiencies I have cited by 1.) Establishing a clear a substantive standard regarding basic care such as food and fluids; 2.) Initiate an appropriate study to clearly identify areas of neglect and abuse that our vulnerable and incapacitated adults face today; and 3.) To establish a federal presumption in our Medicaid and Medicare programs that food and fluids will not be denied absent an explicit wish to the contrary.

Mr. Chairman, these past few weeks have shown us that what we may have considered normal, appropriate care for incapacitated individuals—namely the provision of food and fluids—is now being challenged. Congress must step up to this challenge and be prepared to affirm the full protections and rights of every American but most especially those that are dependent on others. Let it not be said that we ignored so important a value.

Mr. Chairman, thank you for your interest in this subject.